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Therapeutic patient education improves knowledge and skills for patients with chronic spontaneous urticaria

Florence HACARD[1,2,a]
Clemmie MARTIN[1,a]
Virginie VERDU[1]
Arlette MONTAGNON[1]
Frédéric AUGEY[1]
Marion BRAIRE-BOURREL[1]
Jean-François NICOLAS[1,2]
Frédéric BERARD[1,2]
Audrey NOSBAUM[1,2]

[1] Allergy and Clinical Immunology Department, Lyon Sud University Hospital, Hospices civils de Lyon, France
[2] CIRI, Centre International de Recherche en Infectiologie, Univ Lyon, Inserm, U111, Université Claude Bernard Lyon 1, CNRS, UMR5308, ENS de Lyon, F-69007, Lyon, France

[a] These authors contributed equally.

Reprints: A. Nosbaum
<audrey.nosbaum@chu-lyon.fr>

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Background: Therapeutic patient education (TPE) allows patients to better understand their disease and cope with treatment. TPE programmes have not yet been evaluated for chronic spontaneous urticaria (CSU). *Objectives:* To investigate the cognitive and behavioural impact of TPE on CSU patients. *Materials and methods:* CSU patients were selected who completed a TPE programme. A pre-post comparison was performed using a skill/knowledge questionnaire, based on six educational objectives, before and after the intervention. The course of CSU was also analysed, according to daily hive count and itch intensity. *Results:* All of the 61 enrolled patients improved their knowledge and skills following TPE, with greatest improvement in itch management and use of alternatives to scratching. CSU activity was reduced at the end of the programme in 60% of patients. *Conclusions:* TPE improves knowledge and skills for CSU patients. Further research is needed to demonstrate the positive impact of TPE on CSU activity.

Key words: therapeutic patient education, chronic spontaneous urticaria, knowledge, skills

Chronic spontaneous urticaria (CSU) is characterized by the occurrence of itchy wheals and/or angioedema (itchy wheals, angioedema or both), lasting for more than six weeks. The quality of life of patients with CSU is substantially impaired due to its long duration and changeable symptoms, and severe impact on sleep, interpersonal relationships, and appearance [1, 2]. Anger, shame, and fear, especially fear of dying from angioedema, are the most chronic dominant emotions felt by CSU patients [3]. However, fears are largely misplaced, as CSU is not a life-threatening disease.

Treatment of CSU is less satisfactory than it could be [4, 5]. Quality of care still depends on the skills of patients for day-to-day management of the disease, in addition to drugs. Although healthcare providers, in general, and physicians, in particular, are competent in diagnosis and treatment choice, they are usually never taught about methods of efficient long-term care. Therapeutic patient education (TPE), which helps patients with chronic disease to gain skills that will improve their everyday life, is critical in this process [6].

TPE is a complex intervention involving multiple activities, such as psychological support, hospital and procedural organization, and health- and disease-related behaviours [7]. It allows patients to better understand their disease and cope with treatment, in order to improve quality of life and treatment adherence. Unlike TPE programmes for other pathologies, the development of TPE in CSU remains poor and its impact has not yet been studied. We decided to evaluate the impact of TPE on CSU using the educational programme running in our Allergy and Clinical Immunology Department, dedicated to skin inflammatory diseases and accredited by the French Regional Health Agency. We conducted a pre-post comparison in adult patients with CSU to investigate whether this educational programme adds value to knowledge on the disease and its management. The effect on patients' skills and knowledge of CSU were measured as primary outcome after intervention. Furthermore, changes in disease activity and the effect on therapeutic need were also assessed.

Methods

Patients

An uncontrolled retrospective study was performed from 2014 to 2016. Patients were referred to our department by general practitioners, dermatologists, and allergologists. The following inclusion criteria were used:

- having and coping with urticaria for a period of at least six weeks or more;
- a diagnosis of CSU, as defined by the EAACI/GA2LEN/EDF/WAO guidelines;
- experiencing failure of dosed-up antihistamines or a poor quality of life;
- needing to better understand their disease;
- age over 18 years;
- completion of the entire educational programme.

All patients participating in the programme were asked for their verbal informed consent.

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Intervention: therapeutic patient education

The TPE programme included four steps over six months [7]. The two first stages occurred during an individual one-hour session, led by a nurse. The first step, called “educational diagnosis”, was aimed at understanding what the patient already knows, believes, fears, and hopes for, in order to determine the patient’s difficulties and resources. In the second step, educational objectives (*i.e.* the required skills) were determined with the patient using a skill/knowledge questionnaire (*tables 1 and 2*). This stage establishes which skills the patients need in order to better manage their disease, according to their difficulties and resources. The third step concerned the acquisition of skills and knowledge by the patient. For this step, an individual written plan of action was developed for patients according to their characteristics. During this step, health providers used a number of different educational resources (patient-centred communication techniques, practical demonstrations, and educational tools) over four two-hour workshops (*figure 1*). Workshops took place with small groups of six to eight patients and were run by an expert and a group leader. These sessions involved trained multidisciplinary caregivers, including doctors (dermatologists and allergologists), nurses, and psychologists. The aim of each workshop was to establish an interactive exchange between the patient and the caregiver based on a given theme:

- how to name the disease; triggering factors, treatments, and side effects;
- pathophysiology and chronic nature of CSU;
- management of itch and alternatives to scratching;
- stress management and relaxation;
- diet balance and dietary recommendations.

The fourth step, following TPE, concerned its assessment using a similar skill/knowledge questionnaire (*table 2*). Biomedical criteria were also recorded during an individual one-hour session, led by the same nurse having assisted in the educational programme. This programme conforms to national specifications (article L.1161-2 of the French Code of Public Health) and was accredited by the Auvergne Rhône-Alpes Regional Health Agency (validation number: 2010/PPS/ETP/4519/69).

Table 1. The skills and knowledge evaluated during therapeutic patient education (TPE) for chronic spontaneous urticaria (CSU), adapted from [7].

	Objectives
Knowledge of the disease	1. Knowing how to explain the disease and its mechanism to others 2. Recognize the different lesions
Practical skills	3. Knowing how the treatments work and how to use antihistamines 4. Knowing how to manage a flare-up and adapting the treatment to disease activity 5. Managing itch and using alternatives
Relational skills	6. Knowing how to manage stress, difficulties and emotions

Outcomes measures

The primary outcome was to analyse changes in patients’ skills and knowledge after TPE. A pre-post comparison was performed using the skill/knowledge questionnaires (*table 2*). Two questionnaires were completed for each patient at the second and fourth steps of the TPE programme by the same investigator. Each questionnaire included six established objectives, concerning knowledge of the disease and practical and relational skills (*table 1*) [7]. Each item was scored on a scale of 0 to 2 regarding the acquisition of skills: 0 = not acquired, 1 = partially acquired, and 2 = acquired. The mean score was assessed objectively based on two points, and the total score per patient based on 12 points, before and after TPE.

The secondary outcomes were the impact of TPE on disease activity and therapeutic need. Disease activity was evaluated at each session using the UAS7 (Urticaria Activity Score), according to daily hive count (0, 1-6, 7-12, > 12) and daily itch activity (none, mild, moderate, severe), reported by the patient over seven days. According to the UAS7 score, CSU activity was classified as low (< 15), moderate (15-27), or high (> 27). We evaluated the therapeutic need according to the therapeutic prescriptions of patients. Treatments were classified following the therapeutic algorithm of EAACI/GA2LEN/EDF/WAO guidelines [8]: no treatment, H1-antihistamines (H1A) as a single dose, dosed-up H1A (up to four doses), H1A combined with montelukast (MTK), and other treatments (omalizumab, cyclosporine, and methotrexate). Disease activity and treatments, before and after TPE, were compared.

Statistical analysis

Data were analysed using Student’s *t*-tests (Prism, GraphPad Inc.). Associations between variables were analysed using the Spearman’s correlation coefficient. Statistical *t*-tests with *P* values less than 0.05 were considered significant.

Results

Participant characteristics

A total of 1,200 CSU patients were under care in the department during the survey, of whom 61 patients (5%) followed the entire educational programme. Forty-two females (69%) and 19 men (31%) were included, with a mean age of 42 years old (range: 23 to 86 years). Distribution of males and females was in line with the prevalence of CSU among the European population and mean disease duration was five years (range: 3 months to 39 years) [8].

Acquisition of knowledge and skills based on TPE

The TPE programme aims not simply to provide information or advice, but entails the transfer of skills from a trained caregiver to the patient. To address this, we used an evaluation questionnaire for skills and knowledge, supervised by a nurse practitioner. The questionnaire was completed during the one-hour face-to-face sessions before and after

Table 2. Skill/knowledge questionnaire and its scoring, completed by each patient before and after therapeutic patient education (TPE), according to the six TPE objectives depicted in *table 1*.

Questions	Level of acquisition		
	Not acquired	**In progress**	**Acquired**
How to explain your skin disease and its mechanism	0 point	1 point	2 points
What are the different lesions of CSU?	0 point	1 point	2 points
How to use the treatment and how it works	0 point	1 point	2 points
How to manage a flare-up and adapting the treatment to disease activity	0 point	1 point	2 points
How to manage itch and use alternatives to scratching	0 point	1 point	2 points
How to manage stress, difficulties and emotions related to CSU	0 point	1 point	2 points

CSU: chronic spontaneous urticaria.

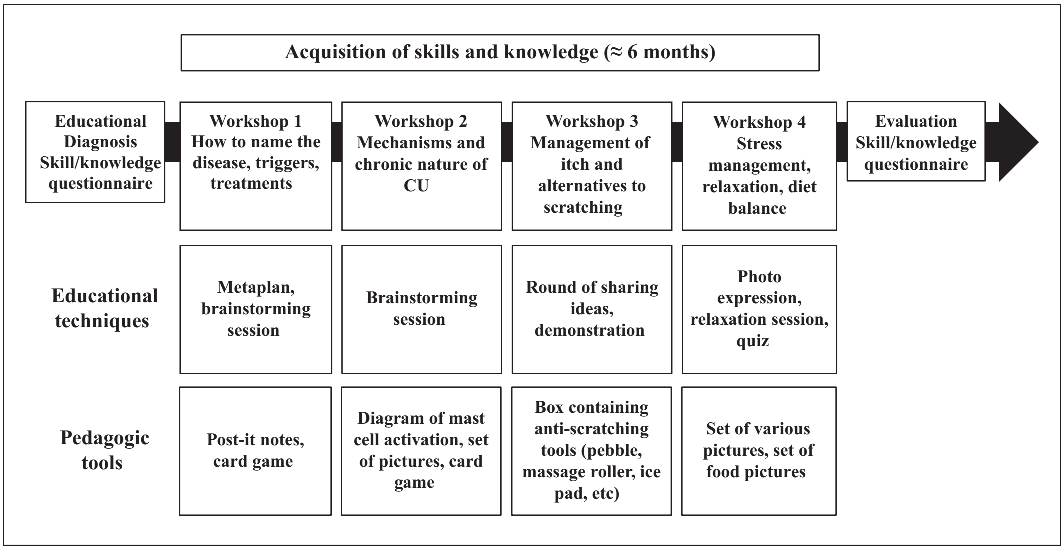

Figure 1. Therapeutic patient education (TPE) process for patients with chronic urticaria. Each workshop comprised of specific educational techniques and pedagogic tools.

Table 3. Overall evaluation of skills and knowledge before and after therapeutic patient education (TPE), expressed as mean score according to objective, ranging from 0 to 2 for the 61 patients.

Objective	Before TPE	After TPE	Mean difference	*P*
1	0.24	1.67	1.43	<0.0001
2	1.67	2.00	0.33	<0.0001
3	0.65	1.88	1.23	<0.0001
4	0.34	1.69	1.35	<0.0001
5	0.34	1.90	1.56	<0.0001
6	0.95	1.80	0.85	<0.0001

TPE. Six educational objectives were scored. The mean score for each objective significantly increased after TPE (*table 3*). The greatest improvement corresponded to objective 5, with a 1.56-mean difference after TPE ($P < 0.0001$). This item dealt with the management of itch and its alternatives, for which an entire two-hour workshop was dedicated. Moreover, the analysis of individual data showed that the total score for each patient significantly increased after TPE with a mean difference of +6.754 (6.319-7.18; $P < 0.001$) (*figure 2*). This suggests an individual benefit for the entire group and progress was seen for all CSU patients. In other words, each participant improved his/her knowledge and practical and relational skills.

Reduced CSU activity after TPE

The next question was to assess whether TPE allows for better control of CSU activity. Three to six educational objectives (objectives 3, 4 and 5) (*table 1)* concerned the therapeutic management of CSU. First, we studied modification of treatments before and after TPE. There was no change in prescription in 29 patients (48.5%). However, treatment was reduced in 16 patients (26.7%) and increased in 15 patients (25.0%) after TPE; the number of patients taking the different treatments before and after TPE is outlined in *figure 3A*. As well as H1A, other treatments were also increased following TPE; 13 patients (21.3%) received

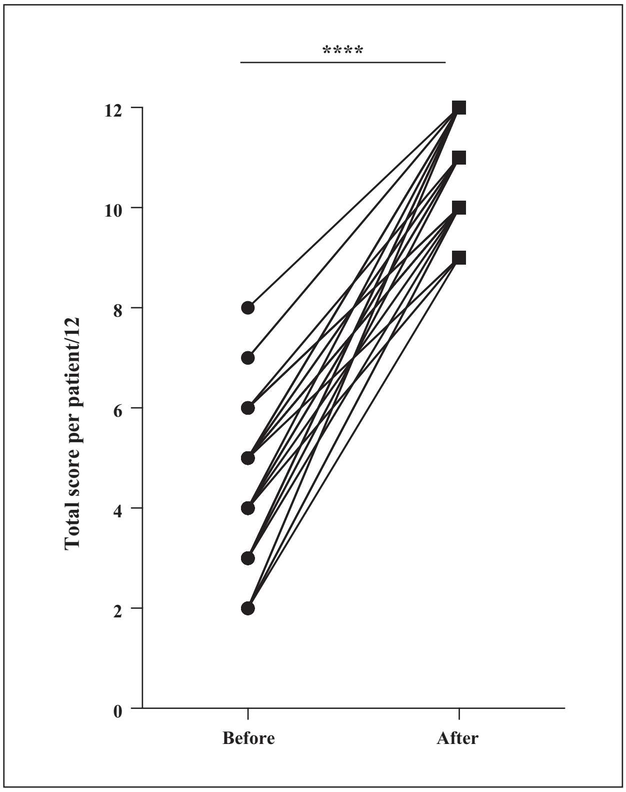

Figure 2. Individual evaluation of skills and knowledge before and after therapeutic patient education (TPE). Results are expressed as total score per patient, ranging from 0 to 12; **** $P < 0.0001$.

immunosuppressive drugs (cyclosporine and methotrexate) or omalizumab (an anti-IgE antibody) after TPE compared to four patients (6.5%) before TPE. However, the prescription of these drugs is restricted, and essentially only available in hospitals. As TPE should not be separated from drug management of UC, these data indicate a successful partnership between patients and their medical team, to adapt treatments (objective 4). Furthermore, seven patients (11.5%) after TPE *versus* three patients (5.0%) before TPE had no treatment. Similarly, 13 patients (21.3%) after TPE *versus* 10 patients (16.4%) before TPE were treated with only a single dose of H1A, suggesting that, after TPE, CSU requires less therapeutic control.

Moreover, we assessed the course of CSU activity over the period of TPE. Although activity of two patients remained severe, the change in CSU activity was highly significant after TPE for the majority of patients (60.6%), with less patients with moderate and severe symptoms (*figure 3B*). Importantly, CSU was completely controlled in 15 patients (24.5%) at the end of the intervention, *versus* three patients (5.0%) before TPE (*figure 3C*). The disease activity did not correlate with acquisition of an individual level of skill or knowledge after TPE; the Pearson's correlation coefficient was $r = -0.17$ ($P = 0.19$) between CSU activity and the total score per patient (data not shown). Since a clinical improvement was reported in 60.6% of patients and only nine patients (14.7%) received more intense therapy (introduction of cyclosporine, methotrexate or omalizumab), the drug effect alone may not explain the overall improvement

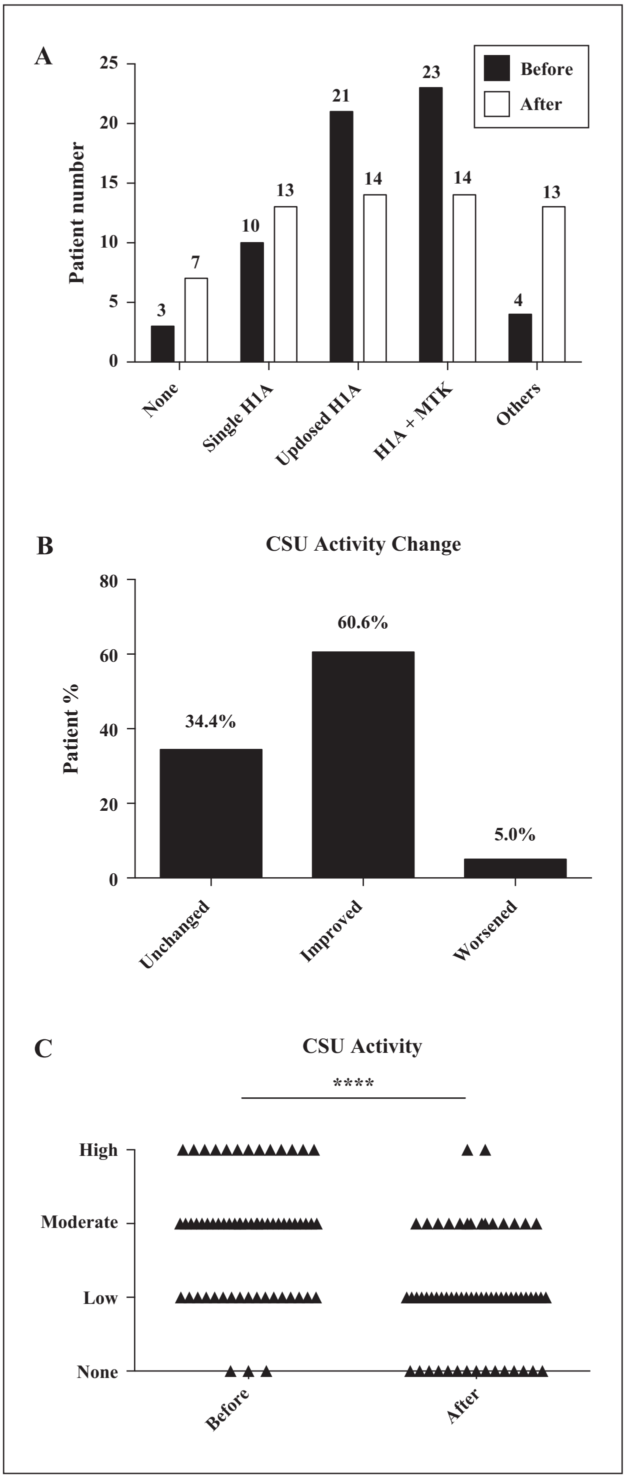

Figure 3. Evaluation of treatments and chronic spontaneous urticaria (CSU) activity during therapeutic patient education (TPE). **A)** Number of untreated patients and patients treated with a single dose of H1-antihistamines (H1A), dosed-up H1A (up to four doses), and H1A combined with montelukast (MTK) or with other treatments (omalizumab, cyclosporine, methotrexate, dypiridamole) before and after TPE. **B)** Change in CSU activity after TPE. Results are expressed as percentage of patients. **C)** Disease activity before and after TPE. Each triangle represents a patient; $n = 61$ patients; **** $P < 0.0001$.

in CSU activity (*figure 3A, B*). Hence, a significant clinical improvement in CSU was apparent after TPE, irrespective of the success of drug therapy.

Discussion

The aim of this study was to gain insight into the impact of TPE on skills and knowledge of CSU patients as well as CSU activity. According to an analysis based on a questionnaire, TPE significantly improved knowledge and behaviour of CSU patients, and was associated with clinical relief. The main gain concerned the management of itch, allowing for less discomfort. Although effects of TPE have been previously reported in patients with chronic inflammatory skin conditions, such as atopic dermatitis, this is the first study reporting such findings in CSU [6].

A clinical improvement in CSU activity was seen after the six-month period of TPE intervention. This improvement may be due to a direct effect of TPE, with better management of aggravating and stress factors, as well as better drug adherence and therapeutic management. However, a spontaneous remission of CSU cannot be ruled out for some patients. Indeed, the rate of spontaneous remission of CSU at one year is approximately 30%. The reported average duration of CSU is two to five years, and our patients already had a mean duration of five years for their disease [9]. Further randomized, controlled trials with a control group without TPE intervention are needed to characterize the contribution of TPE in CSU control, relative to the natural course of the disease.

In order for the TPE process to be of high quality, it should include an individual assessment to measure the effects of the programme. We used a skill/knowledge questionnaire before and after TPE, which provided important data. However, TPE is complex and has different interlinking parts, and a large set of criteria would provide a larger amount of information about TPE efficacy [7, 10]. Validated quality of life and clinical scores (using *e.g*. the Chronic Urticaria Quality of Life Questionnaire [CuQoL], the Dermatologic Quality of Life Index [DLQI], the UAS7, and the Urticaria Control Test [UCT]), appropriate psychological scores, and an evaluation of medico-economic impact could be of interest [7, 8].

While TPE is a time-consuming and costly process, the development of TPE for CSU is progressing with visible gains. Recently, counselling activities have been listed by the Global Allergy and Asthma European Network (GA2LEN) in the 32 requirements to become a GA2LEN Urticaria Centre of Reference and Excellence [11]. We hope that TPE may be added to this list of requirements, once it is well established and ready to be culturally adapted and installed on a global scale. ■

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